Parent activism and social environment: grounded situational analysis

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Abstract

Despite the recent growth of scholarship on parent activism related to disability, the existing literature tends to focus on specific organizations and time periods and draw on a social psychological approach to examine the motivations of parents in becoming activists. This paper considers disability activism as a field of social movement organizations and focuses on disability organizations led by parents and their relationship to organizations led by activists with disabilities. Using qualitative methods informed by theoretically focused coding and grounded situational analysis, we examine the public framing of four national parent-led organizations that are politically prominent. Through this field approach, the analysis reveals the diversity of parent-led organizations, commonalities and the fault lines among these organizations, and the factors which effect the likelihood of alliances between organizations led by parents and those led by activists with disabilities.

Keywords: parent activism; social movements; alliance

Introduction

The role of parents of children with disabilities in disability activism has provoked contention among scholars. Some scholarship positions parents as vibrant, path-blazing advocates who fight selflessly for the rights and needs of their children (Blum, 2007, 2015; Jones, 2010). Other work characterizes parents and their organizations as likely barriers to the empowerment of people with disabilities, especially insofar as parents espouse models of disability rooted in tragedy, medical narratives, and paternalism (McGuire, 2016). Increasingly, scholarship has attempted to resist a polarized portrayal of parents as either martyrs or oppressors, and instead to explore the complexity of parents' activism and their conceptualizations of disability rights, advocacy and justice (Carey & Lu, 2014; Ong-Dean, 2005; Prussing et al., 2005; Rogers, 2011). Parent activists and organizations led by parents (OLPs) vary tremendously in their commitment to and understanding of disability activism as expressed by organizations led by people with disabilities (OLPwD). Even within any given OLP, they often present contradictory messages and display organizational strategies that seem to promote a rights agenda while undercutting it in other ways.

Despite the recent growth of scholarship on parent activism related to disability, the existing literature tends to focus on specific organizations and time periods, such as parent activism in the child guidance movement, institutionalization and deinstitutionalization, and autism awareness. Moreover, its approach tends to be social psychological, examining the motivations, paths, and frames of parents as activists. Here, we build upon existing literature by considering disability activism as a field of social movement organizations and focusing on OLPs and their relationship to OLPwDs. This field approach reveals the diversity of OLPs, commonalities in the fault lines among organizations, and, ultimately, the factors that affect the likelihood of alliances between OLPs and OLPwDs.

Parent Activism And Disability Activism

Often spoken about as «a» singular movement, the Disability Rights Movement (DRM) encompasses many loosely aligned movements and organizations with a decentralized structure that provides the freedom to pursue rights and/or justice agendas unique to specific populations which potentially foster collaboration among diverse organizations to work towards shared goals (Barnartt & Scotch, 2001; Block, Kasnitz, Nishida, & Pollard, 2016; Fleischer & Zames, 2011; Longmore, 2003; Mingus, 2010; Nielsen, 2012; Pelka, 2012). While diverse, scholars imagine these often distinct movements as «a» movement because of a broad sense of shared goals and principles and the growing collaboration across groups across time (Nielsen, 2012; Pelka, 2012). The diversity, though, leaves open the question as to what organizations «count» as part of the movement. Do charities, professional groups, parent organizations, and health-related organizations, for example, «count» if they claim to work on behalf of people with disabilities? James Charlton (2000) argues that disability rights organizations share a focus on empowerment and human rights, independence and integration, and self-help and self-determination as defining features, summed up in the motto «Nothing About Us Without Us.» Similarly, Paul Longmore (2003) suggests that disability rights activism shares the following features: the use of the social model to reform society, the use of the civil rights frame to demand the rights and means to participate in society, and the quest for individual and collective empowerment.

How do OLPs relate to this structure and the priorities laid out by Charlton and Longmore? Much scholarship has documented the key role of parents in developing and applying the civil rights frame to win disability rights, including the rights to education and to live in the community (Carey, 2009; Jones 2010; Schwartzenberg, 2005). According to Fred Pelka (2012:131), the work of parents in fighting for disability rights «can hardly be overstated.» Sociologist Valerie Leiter (2012) posits three waves of the disability rights movement: the first led by parents of children with disabilities, the second adults with physical disabilities, and the third featuring coalition building across parents, adults with a variety of disabilities, and professionals. Rather than a «wave» approach, Kim Nielsen (2012) describes the work of multiple distinct movements focused on disability rights in the 40s, 50s and 60s, including parent activism, which later grew to include cross-disability organization- and coalition-building. Although distinct in the ways they present disability history, these works all position parents as key participants in creating and maintaining the DRM.

Yet, many works on the DRM have little to say about parent activism. Although Pelka (2012: 131) dedicates a chapter to parent activism, he explicitly focuses the vast bulk of his collection of oral histories documenting the DRM on the voices of the disabled community, «those who had most at stake in the success or failure of the movement» (ix). In their history of the DRM, Fleischer and Zames (2011) briefly discuss the importance of parent

activism in achieving the right to education and in deinstitutionalization, but accord it very little attention in the scope of their book. Charlton (2000) does not speak about parent activism at all in his review of disability activism, nor does he include OLPs in his typology of disability rights organizations. This trend reflects the fact that the relationship between able-bodied parent activists and activists with disabilities is at times tenuous, marked by caution and at times frustration.

This tension is explained in part by the fact that parents and people with disabilities may have divergent or competing interests, and in part by the tendency that parents tend to have greater economic and political resources than people with disabilities and thereby, even with the best of intentions, may overshadow or subvert the voices of people with disabilities as leaders of their own movement (Pelka, 2012:131). The motto «Nothing About Us Without Us» demands self-determination, which is potentially undercut by the power of parents to determine disability policy. In other words, the very presence of OLPs fighting for disability rights and justice threatens to undermine the authority of people with disabilities to lead their own movement and determine the policies that most affect them. Parents may claim the symbolic authority of speaking for people with disabilities (Charmak, 2008; Rosqvist et al., 2015); they may present their own interests framed as the needs and rights of their own children, without recognizing potential conflicts of interests (Kittay, 2011; Underman et al., 2017).

Tensions between parents and activists with disabilities are further exacerbated by the paternalistic and medical perspectives that at times permeate parent activism. Parents fight for the well-being of their children, as well as the well-being of themselves and their families, but they do so in a neoliberal context propagating the doctrine of «child optimization» via professional and scientific intervention (Blum, 2015; Pitts-Taylor, 2010). Beginning in the late 19th and early 20th century, mothers (of children with and without disabilities) were increasingly expected to harness the power of science in raising their children, a trend referred to as scientific motherhood (Apple, 2006; Pierce, 2008). As medical professionals claimed expertise in childrearing and state systems like education and social welfare created professional hierarchies in charge of monitoring and surveilling children and their families, mother-blame became rampant (Jones, 1998; Ladd-Taylor & Umansky, 1988). «Bad» mothers created and perpetuated disability, while good mothers strove to erase disability through a commitment to the regimes of science (Jones, 1998; Landsman, 2009; Neely-Barnes et al., 2011; Sousa, 2011).

Today's parents are expected to learn cognitive, biological, and psychological science; manage the array of medications and therapies and their consequences; and manipulate and mold their children's bodies and minds in order to optimize their neural and physical capacity (Blum, 2015; Mauldin, 2016; Pitts-Taylor, 2010; Singh, 2013; Timberlake et al., 2014; Wall, 2010). For disabled activists, parents too often internalize the value of «child optimization» with associated values of eradicating or hiding the disability and striving at all costs to produce the ideal «normal» child (Kittay, 2011; Rembis, 2016). In doing so, parents cast the disabled child as the problem to be overcome, rather than the ableism, social exclusion, and cultural devaluation of disability that produce systemic inequality (McGuire, 2016; Richter, 2016).

Child optimization isn't just the fantasy born of narcissistic parents; it is driven by a highly competitive, neoliberal society in which only a few succeed and the consequences of failure are tremendous (Fritsch, 2016). Neoliberal economics encourage laissez-faire capitalism, privatization, and decreased government spending on social programs, alongside an ethos of individualism (Erevelles, 2011; Russell, 1998; Russell & Malhavi,

2002). In this context, people with disabilities are denied social supports yet encouraged to enthusiastically locate and even create their opportunities for success. Families are called upon to teach their children entrepreneurial ways, to create opportunities for them to thrive, and to manage the numerous transactions involved in care, treatment, and attaining an «independent» life. Mothers exist in a bizarre nexus between the unflinching demands of selflessness imposed on mothers to create the best lives for their children and the neoliberal ethos of individualism, self-interest, and competition for which they are preparing their children (Carey, 2014; Hayes, 1996).

Shaped by this context, mothers of children with disabilities are expected to take on the role of «advocate» within the repertoire of intensive mothering (Hayes, 1996; Landsman 2009). In her classic study of parent activists, Darling (1988) described the entrepreneurial path taken by parents of children with disability who find that their old networks and reliance on professionals are not useful in meeting the challenges they face; they are instead pulled toward activist networks through which they can gain needed skills and learn how best to navigate through and advocate in a world that largely excludes their disabled child. Although described by Panitch (2008) as «accidental activists» because few parents had an interest in disability politics prior to their role as parent, many parents also describe feeling compelled to serve as an advocate. Sociologist Dennis Hogan (2012) argues that national policies of deinstitutionalization placed significant responsibilities on families to provide care, yet did little to provide supports for families to accomplish this task. Thus, he states that the organization of resources required to access diagnosis, medical care, insurance, education, adult residential supports, employment, and long term care all present challenges «incongruent with the policy of emancipation» (p. 13). These parents must become lay doctors, nurses, therapists, educators, service managers, and advocates, all while remaining a parent to their child. The challenges of this situation are especially significant for parents of children with complex and significant disabilities who provide intensive in-home support while also managing resources across multiple institutional sites and service providers. Also, parents with less social capital are disadvantaged in the individualistic competition for resources, creating an unfair playing field in which white, wealthy parents may successfully use their privilege to hoard disability services/resources for their children (Ferri & Connor, 2006; Ong-Dean, 2009).

Increasingly parents identify advocacy as part of their parenting role, but the meaning and goals of advocacy are shaped by macro organizational structures and discourse. For example, The Arc encouraged parents to challenge institutionalization in the late 1960s and 70s, actively explaining to parents the range of institutional abuses, the fundamental problems with congregate care, and the role of preserving the institution in diverting funding for community care (Carey & Gu, 2014). In contrast, Anne McGuire's (2016) work on autism campaigns reveals a darker side of parent activism. Autism campaigns have presented autism as a thief robbing a child of his/her life and as a terrorist holding children and families hostage. Such starkly negative depictions of disability legitimate policies to pursue eradication of the disease and potentially the people with the disease, increasing the stigma, exclusion, and even violence experienced by autistics.

The substance of parent activism is multifaceted and often contradictory. Parents may be less guided by a single philosophical stance than by the creative pursuit of a varied set of goals, through multiple strategies, that they deem appropriate for the best interests of their child and for their family (Goodley, 2007). For example, they may adopt a medical narrative to «erase» disability, but they may also use medicalization as a means to combat

institutional discrimination and attain a diagnosis that can be the gateway for access to disability rights, services, and accommodations (Landsman, 2009; Mauldin, 2016; Ong-Dean, 2009; Prussing et al., 2005; Singh, 2013). Parents' activism may engage with neo-liberalism in one area such as advocating for Medicaid waivers which allow public dollars to be allocated at the direction of individual consumers to create their own individualized support system, but alternatively may rely on the ideas of vulnerability and dependence to demand a broad social safety net such as income supports (Jones, 2010; Panitch, 2008). 2 Typically studies of parent activism examine a single disability group or organization, and often they are based on a micro-level analysis of parental perspectives and motivations. The scope of these studies rarely shines light on the macro-level complexity and diversity of parent activism.

Fields, Alliances, And Frames

Large social movements are rarely monolithic. They tend to be complex and involve a field of organizations with different positions in relation to each other (Van Dyke & McCammon, 2010; Zald & Mayer, 1997). Disability activism is no exception. It is sufficiently diverse and complex that it might be considered a set of related movements rather than a single movement. It includes a variety of organizations (Charlton, 2000; Barnartt & Scotch, 2001). Some are cross-disability, others single-disability. Some are international, others national, and others organized at the state or local level. Some limit themselves to legitimate channels of political influence, while others engage in civil disobedience and radical protest. They may variously focus on rights, social justice, self-help, awareness, and/or the arts. Some are led by people with disabilities, others by professionals, and others by parents.

This diversity potentially creates competition and conflict but also potentially serves the movement to move forward on multiple fronts through productive alliance. In this paper, we explore the relationship between OLPs and OLPwDs. Our exploration is oriented toward the following questions: To what degree do OLPs share the same core tenets as OLPwDs? To what degree do OLPs ally with OLPwDs? To what degree do OLPs actually pursue interests that diverge from OLPwDs, causing them to be positioned as opponents of the DRM?

Sharing a frame is a major factor in organizational alliance within a broader social movement (Gerhards & Rucht, 1992; McCammon & Van Dyke, 2010; Staggenborg, 2010). In any given social movement field, organizations may share an underlying frame which sets forth explanations and solutions to the «problem» at hand, or they may have fundamentally different understandings of the problem, its cause, and/or its solutions (Snow et al., 1986). Divergent frames breed competition regarding resources, control of the public discourse, and symbolic and organizational authority; however organizations with divergent frames may nevertheless form strategic alliances based on specific shared goals and responses to outside threats (Staggenborg, 2010). For example, the Christian Right and disability activist organizations make «strange bedfellows,» yet came together in the 1980s to fight against euthanasia and the denial of medical treatment for infants with disabilities and in recent politics to challenge abortion based on «genetic abnormality» (Giric, 2016). Although allied to protect fetuses and infants with disabilities, the DRM's demand for inclusion is often at odds with the Right's focus on deregulation, the reduction of taxes, and the privatization of services and supports.

For «new social movements» that focus on creating social change in identity, lifestyle, and culture, rather than striving to achieve straightforward policy goals or address material inequality alone, issues of voice and symbolic ownership of an issue are

also pressing (Pichardo, 1997). New social movements seek reliable allies who not only share a specific goal or a broader frame around that goal but also display a commitment to the identity politics of the movement. This commitment entails respecting who «owns» the issue, placing the value of collaboration at times above one's own specific interests, and sharing a sense of grievance when an ally is wronged, even if it doesn't immediately affect you (Beamish and Luebbers, 2009). The «bridging work» of alliance, then, shows that organizations care about the issue, the peopleinvolved in the issue, and the alliance itself (Beamish & Luebbers, 2009).

The capacity to build diverse and strategic alliances is central to the success of long-standing social movements, and, for disability activists, parents are an important potential ally, bringing to the fight a passionate interest, deep needs, symbolic authority and persuasive power, and economic and political resources. However, the political power of parents is also a potential threat to disability rights activists insofar as parents undermine and oppose disabled activists. This paper then seeks to explore a range of OLPs, the degree to which their frames align with the frames used by OLPwDs, and the actual occurrence (or not) of alliance.

Methods

To examine the social movement frames used by OLPs, we first chose our sample. We examined the public framing of four OLPs that are national in scale and politically prominent: United Cerebral Palsy (UCP), The Arc (formerly The Association for Retarded Citizens), The National Alliance on Mental Illness (NAMI), and Autism Speaks. In addition, several other national parent-led organizations were included when useful for comparison and contrast, including American Society for Deaf Children, Hands & Voices, National Down Syndrome Association, National Organization of Parents of Blind Children, National Federation of Families for Children's Mental Health, and VOR (formerly Voice of the Retarded). Each of these organizations, their mission, and year of founding are listed in Table 1. This list, while not exhaustive, covers a diversity of nationally prominent parent-led organizations. Although parent-led organizations proliferate on the local and state-levels, we only considered national organizations.

Table 1. Organizations Led by Parents (OLPs)

Organization	Founded	Mission
United Cerebral Palsy (UCP)	1949	Service delivery & rights advocacy for persons with CP and other development disabilities.
The Arc	1950	Service delivery & rights advocacy for persons with intellectual disabilities.
National Alliance on Mental Illness (NAMI)	1979	Grassroots advocacy for people with mental illness.
Autism Speaks	2005	Research & awareness related to autism.
American Society for Deaf Children	1967	Advocacy for language-rich environments including American Sign Language (ASL).
National Down Syndrome Society	1979	Advocacy for rights and well-being of persons with Down Syndrome.
VOR (formerly Voice of the Retarded)	1983	To challenge deinstitutionalization & fight for service options including large-scale facilities.
National Organization of Parents of Blind Children	1983	Parent division of National Federation of the Blind

(NOPBC)		
National Federation of Families for Children's Mental Health	1989	Focuses on issues of children with mental health concerns and their families.
Hands and Voices	1997	Provides resources for all families of deaf & hard of hearing children regardless of communication methodology.

To examine alliance with OLPwDs, we looked to the positions advocated by the National Disability Leadership Alliance (NDLA), which describes itself as «a national cross-disability coalition that represents the authentic voice of people with disabilities, composed of 15 national organizations run by people with disabilities with identifiable grassroots constituencies around the country» (National Disability Leadership Alliance, 2017). NDLA includes ADAPT, the American Association of People with Disabilities, the American Council of the Blind, the Association of Programs for Rural Independent Living, the Autistic Self Advocacy Network, the Hearing Loss Association of America, Little People of America, the National Association of the Deaf, the National Coalition for Mental Health Recovery, the National Council on Independent Living, the National Federation of the Blind, the National Organization of Nurses with Disabilities, Not Dead Yet, Self Advocates Becoming Empowered, and the United Spinal Association. While these are not the only organizations led by people with disabilities focused on disability issues, they represent a core set of organizations identified by activists with disabilities that have built a stable coalition on the basis of shared interests in the empowerment of people with disabilities and related goals. Table 2 lists the founding date and mission of each of these organizations. There are of course other disability-related organizations, including those that are predominantly led by professionals such as Easter Seals and Muscular Dystrophy Association. These organizations are considered outside the scope of this analysis due to our focus on parent-led organizations and their relationship with activists with disabilities.

Table 2. Organizations Led by People With Disabilities (OLPwDs)

Organization	Founded	Mission
ADAPT	1983	A national grass-roots community that organizes disability rights activists to engage in nonviolent direct action, including civil disobedience, to assure the civil and human rights of people with disabilities to live in freedom
American Association of People with Disabilities	1995	A convener, connector, and catalyst for change, increasing the political and economic power of people with disabilities
American Council of the Blind	1961	To increase the independence, security, equality of opportunity, and quality of life, for all blind and visually-impaired people
Assoc. of Programs for Rural Independent Living	1986	To advance the rights and responsibilities of people with disabilities in rural America by serving as a center of resources and by leading systems change
Autistic Self	2006	To advance the principles of the disability rights

Advocacy Network		movement with regard to autism... for a world in which autistic people enjoy equal access, rights, and opportunities
Hearing Loss Association of America	1979	The nation's leading organization representing people with hearing loss
Little People of America	1957	Dedicated to improving the quality of life for people with dwarfism throughout their lives while celebrating with great pride Little People's contribution to social diversity
National Association of the Deaf	1880	The nation's premier civil rights organization of, by and for deaf and hard of hearing individuals in the United States of America
National Coalition for Mental Health Recovery	2006	To ensure that consumer/survivors have a major voice in the development and implementation of health care, mental health, and social policies at the state and national levels, empowering people to recover and lead a full life in the community
National Council on Independent Living	1982	To advance independent living and the rights of people with disabilities
National Federation of the Blind	1940	The only organization that believes in the full capacity of blind people, and has the power, influence, diversity, and determination to help transform our dreams into reality
National Organization of Nurses with Disabilities	2003	The voice of disability in nursing - an open membership, cross-disability, professional organization that works to promote equity for people with disabilities and chronic health conditions in nursing through education and advocacy
Not Dead Yet	1996	A national, grassroots disability rights group that opposes legalization of assisted suicide and euthanasia as deadly forms of discrimination
Self Advocates Becoming Empowered	1990	To ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves, opportunities to make new friends, and to learn from their mistakes
United Spinal Association	1946	Dedicated to enhancing the quality of life of all people living with a spinal cord injury or disease (SCI/D)

To focus the analysis of framing, we examined three tenets described in scholarship (Charlton, 2000; Longmore, 2003) as central to the disability activism led by people with disabilities: the prioritization of the social model over medical model, the goal of integration, and empowerment of people with disabilities. We expected a tendency for the tenets to align such that organizations focused on the social model would also advocate integration and foster leadership among people with disabilities, while organizations focused on the medical model would also advocate disability-specific settings and

paternalism. We also expected OLPs that advocated for the social model, integration, and empowerment of people with disabilities would ally with OLPwDs more frequently.

An organization's position may be different from the beliefs and goals of its members. Indeed, it may be that many parents operating on the local level have little understanding of the national political agenda of an organization and/or its position and relationship among organizations in social movement field (Jones, 2010). To capture the public positioning of the organization, we conducted a content analysis of organizational websites and additional public documents. In today's day and age, the website offers a window into «the picture and/or story the organization's leadership would like to show and/or tell to the world» (Egner, 2018). The design, structure, content, and related pathways (to blogs, twitter accounts, documents and resources, etc.) all offer avenues through which to explore the narrative actively constructed for the public (Hine, 2000). In this research project, the overall organization of the website itself was examined as well *as* content areas, including the home page, mission statement, policy goals, research goals and products, resources made available to the public, key issues/initiatives, and other related documents. While some organizations may fail to maintain their websites, the organizations under analysis here are large, active national organizations with informational dissemination as a key part of their mission. Each has staff dedicated to its virtual presence, and each regularly updates their site with timely information.

Materials were downloaded across all sites in June 2017 to provide a snapshot of each organization's public representation at a given time. This means that some issues might be more pressing than typical; in particular debates were raging nationally related to the possible repeal of the Affordable Care Act (ACA). On the other hand, by making sure all materials are from the same time frame, we hope to control for the potential bias if, for example, we downloaded material from one site during the ACA debate and from another site when that debate was resolved and thereby mistakenly thought one organization was more or less focused on health care issues. This «snapshot» approach neglects to attend to the long history across organizations by which their positions and relationships formed over the course of decades, though, which is part of our larger project.

The content analysis combined coding strategies from both grounded theory (Charmaz, 2014; Corbin & Strauss, 2015; Glaser & Strauss, 2000) and theory-driven techniques. Coding was initially thematically focused, specifically looking for material within each key tenet: social model vs. medical model, integration vs. disability-specific settings, and empowerment vs. paternalism. Within each theme, though, the analytic process allowed framings and sub-themes to emerge inductively through detailed grounded coding, building analytic categories, and memo-writing. For example, although we began by sorting information into the broad categories of medical model or social model, through the analysis process we derived five strategic orientations related to this theme.

Clarke's (2005) techniques of situational analysis proved especially useful in conceptualizing and analyzing the complex discourse and positions. Situational analysis attempts to stay true to complexity and analyze, rather than erase, the many ambivalences, multiplicities and contradictions in how collective actors align, frame their views, and act related to their expressed views. Social Arena/world mapping illuminated the complexity of actors, actions, and elements involved in disability politics and the relational position of parent organizations within this field. Position mapping recognizes that «individuals and groups of all sorts may and commonly do hold multiple and

contradictory positions on the same issue,» and disaggregates the position from the actor/collectivity. 3

FRAMING AND OLPs

To briefly summarize our findings, commitment to any given tenet within each OLP is often complex and fluid. Most organizations have some blend of reliance on the social and medical models, a complex or inconsistent stance toward integration vs. segregation, and organizational models that support limited empowerment while also supporting paternalism. OLPs rarely fully embraced one pole of a tenet to the exclusion of the other pole; rather they tend to have a strategic mix to cater to different audiences and issues.

Similarly, while some alignment was found across the tenets (social model, inclusion, empowerment vs. medical model, disability-specific settings, paternalism), this expected pattern was surprisingly inconsistent. Some organizations that relied heavily on the social model had nothing in their bylaws to mandate empowerment of people with disabilities and had few people with disabilities in positions of power. OLPs are passionately driven to create change yet posit a vision at times misaligned with that of core OLPwDs, Thus, from the perspective of OLPwDs—those for whom these tenets are fundamental to their mission and structure—OLPs often fall short, and as such, they are perhaps best understood as «suspicious» allies who «sometimes» offer alliance but other times, in other ways, fail to do so.

That said, some OLPs are much more likely to ally with OLPwDs than others. Some OLPs, despite rhetoric about fighting for the rights of their disabled children, have values and policy positions that are largely incongruent with the core tenets of OLPwDs. Other OLPs share tenets and policy goals with core OLPwDs. Some of these occasionally even engage in «extra-issue bridge work» and use their resources to support an organization or goal even when it wasn't clearly of benefit to their own population. Even the best-aligned OLPs, though, are «sometimes» allies, working alongside OLPwDs but also willing to fight for their own constituencies' interests and power (Rosqvist et al., 2015).

We turn now to detailed exploration of the stance of OLPs regarding each of the core tenets of disability activism: social vs. medical model of disability, integration vs. disability-specific settings, and empowerment vs. paternalism.

Models Of Disability: Social Model And Medical Model

No difference in perspective looms larger in disability activism than the tension between the medical and social models of disability. The medical model views disability as residing within the person and asserts the need for medical treatment and intervention to ameliorate and, if possible, cure or prevent disability. Doing so generally involves diagnosis—a process of identifying a person's deficiencies—and relying on medical professionals, including those who apply medical and quasi-medical technological supports and draw on medical culture and authority, to guide treatment. Thus, the presence of discourse about diagnosis and treatment and medical professionals in leadership are indicators of the medical model. The social model, on the other hand, explores, critiques, and changes the environmental structures, including attitudes, processes, policy, and physical features, and emphasizes fighting for social justice, including greater rights and opportunities for persons with disability to participate in various aspects of social life (e.g., Linton, 1998; Oliver & Barnes, 2012). The social model advocates rights, justice, accommodations, and social supports, rather than medical intervention.

The social and medical models are often discussed as polar opposites, despite theoretical developments that reveal the interaction between the body and environment and the ways in which the context constitutes the body and vice versa (Siebers, 2008;

Thomas, 2002). In practice too, use of these models is not mutually exclusive. Typically, parents use a mix of strategies in pursuit of their and their children's interests, some congruent with the social model and others with the medical model. In this research, we found that OLPs tend to draw from both models, although one model is usually dominant. We identified five configurations of the relationship between the social and medical models in the framings used by OLPs. Any given organization may exhibit multiple configurations, applied to different organizational goals. Although theory and practice may recognize a complex interplay between the social and medical models, model commitment is highly relevant in alliance-building because strong adherence to a medical model is largely rejected by OLPwDs.

Pure Social Model/Demedicalization

Drawing on the social model, this frame focuses almost exclusively on issues of rights and accessibility. In the process of demedicalizing disability, the organization de-emphasizes delivery of information on medical practice and treatment, bio-medical research and policy, and collaboration with medical professionals. Organizations may also directly challenge the medical perspective and authority claims of medical professionals.

The National Organization of Parents of Blind Children (NOPBC) is an example of an organization that primarily uses a social model/demedicalized frame. The website offers very little medical information (e.g., information on diagnosis, biological causes of blindness, testing, treatments, clinical trials), no discussion or funding of medical research, nor any legislative agenda items focusing on medical advancement. Rather than promote the medical paradigm, when speaking about expertise the website notes that its broader organization, the National Federation of the Blind (NFB), provides access to 50,000 blind people to serve as mentors and role models with information about blindness.

The information provided centers on issues of equality and opportunity, such as education, employment, and on the «'skills and tools of blindness» (e.g., Braille, technology, training, empowerment), which are seen as «essential for the child's success both at home and at school» and best taught by blind people (not sighted professionals). NOPBC believes «that blind people who are taught and who embrace effective non-visual skills, whatever their degree of eyesight, are capable of living a full and satisfying life» (The National Organization of Parents of Blind Children, n.d.). In other words, blind people need the opportunity to thrive as blind people, not contingent on cure.

NOPBC functions as a division of the NFB (one of the organizations in the National Disability Leadership Alliance), and the NFB website similarly rejects the medical model: «Every day we raise expectations of blind people because low expectations create obstacles between blind people and our dreams; blindness is not what holds you back.» Led by blind activists, their mission is to completely integrate blind people into society as equals, and they focus on issues of anti-discrimination and access, not medical intervention. Legislative priorities include issues such as access to technology and publications, employment, air travel equity, voting, and parental rights, with very little attention to medical advancement.

Medicalized Support Of The Social Model

Another frame uses a limited medical model to support what is primarily a social model. Many people with disabilities and their family members are concerned with issues of social participation, opportunities, and rights, but also use the medical system to claim rights and access funding and services that support participation, such as community habilitation, vocational rehabilitation, and personal assistance. These activists challenge

medicalization but realize their dependence on it and its power to fund targeted services and supports for people with disabilities. This «devil's bargain» occurs with many achievements of the Disability Rights Movement, such as the Americans with Disabilities Act that relies on diagnosis to access rights and, in defining disability, both challenges and reinforces a deficit approach (Silvers & Francis, 2000). Similarly, Section 504, one of the earliest civil rights accomplishments, is part of the 1973 Vocational Rehabilitation Act, and therefore uses the laws guiding medical rehabilitation to secure anti-discrimination legislation (Scotch, 1984). The Individuals with Disabilities Education Act, which grants students with disabilities a free and appropriate public education, also relies heavily on diagnosis and evaluation by medical experts to legitimize claims for accommodations and supports.

United Cerebral Palsy (UCP) and The Arc, two of the nation's largest OLPs, both exhibit this approach. Each shows a clear commitment to the social model. Although most children with cerebral palsy receive some sort of medical treatment or therapy, medical treatment is not UCP's main priority. In keeping with the social model, UCP's home page leads with rotating images that declares: «For people with a spectrum of disabilities, our affiliates advance independence and full citizenship[,]... For people with a spectrum of disabilities, life should be without limits[,]... For people with a spectrum of disabilities, the civil rights movement is not over» (United Cerebral Palsy, n.d.). Their history page criticizes the role of medical professionals in institutionalizing and stigmatizing people with disabilities, and explains that UCP's contemporary priority is to open doors to the community through supporting advancements in areas such as home ownership, health care reform, inclusive education, and competitive employment.

Along with their adherence to the social model, UCP and The Arc also have a significant focus on medicalized systems such as Medicaid due to their role in institutionalizing and funding community-based supports and services. During the summer and fall of 2017 the Affordable Care Act and Medicaid were threatened by repeal efforts and budget cuts, and there was an outcry to protect Medicaid-funded services for people with disabilities. The right to live in the community directly hinges on programs funded through Medicaid (Grossman, 2011). As another example, UCP worked on the RAISE Family Caregivers Act which directs the Department of Health and Human Services to develop a strategy to support caregivers providing services in the community. These foci are not principally about direct medical treatment per se, but rather use the bureaucratic framing of services as treatment and the medically oriented infrastructure of policy and funding to support community opportunities and access for people with disabilities.

OLPs are not alone in their willingness to use the medical infrastructure to advance an activist agenda. The most vehement of the disability activist organizations, such as ADAPT, work relentlessly to shift Medicaid funding to community-based long-term care rather than institutional care. Even the largely demedicalized National Federation of the Blind supports the use of vocational rehabilitation, which relies on medical diagnosis and documentation, to gain access to community-based, competitive employment rather than low-wage work in sheltered workshops. Organizations operate within a broad political environment that tie rights and services to medical gatekeeping, and disability organizations have strategically used this association rather than solely pursuing a social model.

Health Care Equity

The medical model and social models are blended in a unique balance in the fight for health care equity. Accepting and valuing disability does not mean that one does not

deserve access to high quality health care on one's own terms. Access to high quality primary and specialized care is limited for people with disabilities in America. Doctors may refuse to see patients with significant disabilities who may need extra time or supports to receive care, and/or they may choose not to accept Medicaid, further restricting access to health care for people with disabilities (Ervin et al., 2014; Krahn et al., 2015). Other barriers to health care abound. It is, therefore, not surprising that many OLPs, including The Arc, UCP, and NAMI, fight to ensure that people with intellectual, developmental, and mental disabilities are not disadvantaged in accessing routine and specialized care. The Arc position states, «The health care system must be aligned to principles of nondiscrimination, comprehensiveness, continuity, appropriateness, and equity. Both comprehensive public and private health insurance must provide for necessary health care without regard to the nature or severity of disability, pre-existing conditions, or other health status» (The Arc, «Life in the Community,» n.d.).

For The Arc, health care equity is one of many equity issues. For NAMI, access to treatment as a fundamental right of people with mental illness is front and center in their platform. NAMI challenges structural biases built into the funding of healthcare that prioritize physical health and deprioritize mental health. They are at the forefront of fighting for «mental health parity,» the idea that health care related to mental illness should be covered by insurance plans to the same extent as health care related to physical illness. NAMI notes that without parity, «mental health treatment is often covered at far lower levels in health insurance policies than physical illness, which means people do not get the care they need to experience recovery» (National Alliance on Mental Illness, «Parity for Mental Health Coverage,» n.d.). Organizations like ADAPT, The Arc and UCP have fought to remove other structural biases in health care, such as the «institutional bias» in Medicaid funding. Medicaid funding prioritizes institutional care, and many disability-activist groups have fought to ensure that funding flows to community-based treatment/services.

Enhancing access to health care may also mean working with and training medical personnel to confront their biases. The National Down Syndrome Society (NDSS), for example, makes a particular effort to engage with medical professionals and shape medical discourse to improve outcomes for people with Down syndrome. Because of the physical markers of Down syndrome prenatally and at birth and the historic stigma against this impairment, children with Down syndrome are particularly susceptible to early institutionalization, out-of-family placement in adoption services, abandonment, and abortion. Medical discourse and practice heighten these risks by defining Down syndrome as a birth «defect,» promulgating testing for defects, neglecting to provide positive information about quality of life and community resources, and discounting the potential for a successful and meaningful life for people with Down syndrome (Parens & Asche, 2000; Thomas, 2017). In response, NDSS trains health care professionals to communicate the value of diverse lives to prospective and recent parents.

Outcomes for Deaf children are also shaped heavily by interaction with medical professionals. The American Society for Deaf Children (ASDC) states that all D/deaf children have a right to be valued and respected regardless of technology usage, to meet and socialize with other deaf children, and to achieve fluency reading, writing, and to their ability, speaking English; yet they recognize that professionals often fall short of advancing these ideals for deaf children. Thus, ASDC directly engages with medical, audiology, and educational professionals to enhance their capacity to be informed of the successes from all walks of life; to recognize the benefits of early language including early ASL; to connect

parents with other parents, Deaf adults and children; and to provide information on schools and organizations related to Deafness. They do not eschew medical intervention or technology, but also argue that intervention/technology does not replace or diminish the need for Deaf culture and ASL.

Medicalization Toward Mitigation And Social Inclusion

A fourth configuration is a pattern in which diagnosis and active medical intervention/treatment are seen as primary routes to greater social participation, inclusion, and status. This frame emphasizes the power of treatment to enhance normalization and decrease physically and socially problematic aspects of a condition, helping a person better function and be accepted in society (Berube, 2016). OLPs using this frame advocate biomedical identification and treatment as a means toward mitigation, normalization, and social inclusion. Unlike the three prior frames, in this frame medical intervention is valued, putting it somewhat at odds with the agenda of core OLPwDs.

NAMI provides an example of an organization that values diagnosis and treatment as pathways to personal well-being and social inclusion. NAMI's mission statement reflects a broad array of goals towards «building better lives for the millions of Americans affected by mental illness, especially those with serious mental illness,» including attention to treatment. NAMI «firmly believes that individuals with mental illness should have access to clinically appropriate medications, evidence-based services and treatment, including psychotherapy, that are provided in a person-centered approach,» and access to a comprehensive array of treatment, services, and supports (National Alliance on Mental Illness, «Policy Platform,» n.d.). For NAMI, increasing access to effective, evidence-based treatment helps to remove the stigma of mental illness, whereas a refusal to acknowledge the value of treatment and medication is itself stigmatizing, subjecting people to a lifetime of suffering without recourse to the same kinds of supports readily given without stigma to people with physical conditions.

They highlight the importance of providing pathways to stigma-free treatment in many ways. For example, in a feature called «You Are Not Alone,» NAMI members tell personal stories of mental illness. In one such story, «How Invalidating my Bi-polar Disorder Invalidates Me,» the author states the many myths s/he must endure such as «you don't need medication,» «just think positive,» «just calm down,» and «you need to do yoga.» Those unfamiliar with bi-polar, she writes, «have no idea how frustrating and exhausting the years of trial and error in medications and treatment can be. Still, I continue to seek treatment because the symptoms of not treating the illness were far worse... For the first time in a long time, I am learning to deal with my feelings, emotions, and moods» (National Alliance on Mental Illness, «How Invalidating,» n.d.). In another featured blog related to minority health, the blogger discusses the stereotype that one can «pray away» mental illness, and instead reassures people that treatment should be an acceptable way to live more active and successful lives.

Autism Speaks promotes the medical model even more strongly (as will be discussed more in the next section). Its website is structured to provide information on diagnosis and treatment, and Autism Speaks' targeted outcomes for the next 10 years include: «a better understanding of the causes and typology of ASD»; diagnosis «before the age of 2»; «access to appropriate intervention, services, and resources immediately following diagnosis» and «throughout their lifetime.» Their priorities do not focus solely on a medical model. They include, for example, the goals of a better quality of life, providing transition planning for independent living, and providing lifelong supports. That said, their discourse clearly values the role of medical research and intervention as a means to

increase quality of life and independence. In a statement on their «commitment to everyone on the autism spectrum,» they state, «… many aspects of autism can be significantly debilitating, and that is why efforts to improve and deliver scientific breakthroughs are so important, with the goal of enabling those on the autism spectrum to be the best they can be—with autism» (Autism Speaks, «For the Record», n.d.).

Mitigation focuses on long-term therapies, supports, and tools to enhance quality of life and inclusion, and many people with disabilities welcome access to these methods when they are useful and chosen. Yet therapies and medicalized supports also have the potential to feel coercive to people with disabilities for whom recovery is required to feel culturally valued and/or to access rights (Clare, 2017). Evans (2017) documents, for example, the ways that people with mental health disabilities are forced to meet «measurable outcomes» (e.g. attending support groups, medication compliance, displaying appropriate behavior) in order to obtain desired housing and services. Thus, social service agencies may use the stages of «recovery» as a way to demand compliance and distribute privileges and basic liberties accordingly. Moreover, medical intervention may come to be seen as the only or the best path to inclusion and quality of life, a view that OLPwDs explicitly critique.

Medicalization Toward Cure And Prevention

This final frame related to the social and medical models prioritizes a medical understanding of the condition at hand and imagines a world that is best without the diseases that «plague» it. Rather than helping one live successfully with any given condition, the goal is instead to remove the condition. This discourse may still challenge the medical community, but the challenge is a call for more medical intervention — more research, treatment, drugs, and prevention. A cure/prevention approach assumes that cure will re-establish a person's access to valued social roles, an alternative to prioritizing social supports, issues of social equity or participation. Eradication is the fundamental goal.

Parents of children with diseases, such as cancer and HIV, tend to have a strong commitment to cure and prevention. The American Childhood Cancer Organization, for example, is «dedicated to fighting this last great disease killer of children.» The goal is to «conquer» cancer, and, in the meantime, to ease the «suffering» of children with cancer and their families. Their «Get the Facts» section focuses on medical issues including diagnosis, treatment options, survivorship and bereavement, and cancer statistics. Their advocacy includes building partnerships with «childhood cancer champions;» collaboration with medical experts, pharmaceutical companies, and government; promoting engagement of lawmakers in the «war» against childhood cancer; and encouraging funding for clinical trials, drug creation, and targeted therapies. In this «war,» the medical community is clearly an ally, although not always an unproblematic one. The problem, however, is seen as the lack of medical/research attention to childhood cancer and the solution is more medical research related to children, and more access to treatment for children.

This model may seem appropriate for cancer, a potentially lethal illness, from which many children experience remission and even cure, and few people would argue that having cancer is a valued form of human diversity. The situation is very different when the model is applied to disabilities that activists see as a valued and lifelong form of human diversity.

Autism Speaks has drawn particular ire from OLPwDs for its reliance on disease discourse in relation to autism and its focus on cure rather than supports and social

justice. Autism Speaks describes autism as a disease, akin to cancer or AIDS. Indeed, the language of «epidemic» is common to raise alarm and dollars for autism bio-medical research (McGuire, 2016). Here the framing as illness arouses great concern because autism is typically considered a life-long disability for which there is no cure, akin to developmental disabilities (e.g., intellectual disability, cerebral palsy), rather than an illness. For OLPwDs, rights, supports, and services enhance quality of life for people with disabilities. Money and political capital poured into the hope of cure, they argue, have yielded little in the way of improved quality of life and instead increases stigma. Neurodiversity activists in the Autism Self-Advocacy Network, for example, challenge whether a cure is desirable, and instead posit autism as a part of human diversity, a different way to think, rather than a defect to be prevented (Autism Now Center & ASAN, 2014; Bascom, 2012).

The 2009 Autism Speaks film, I am Autism, offers a striking example of the problems of applying an illness perspective to disability. The film was written and produced by parents of children with autism to raise awareness of a «global autism epidemic» (McGuire, 2016). This film presents autism as a thing—a disease—separate from one's child that invades and can be identified, attacked, and killed, a thing that vigilant parents can be victorious over and rescue their real children, their non-autistic children. As we can kill the cancer and recover our suffering children, we can kill the autism and recover the non-autistic child. But autism is a constitutive part of someone; it affects the way they think, interact, and perceive. This is not to reduce people to their autism, but it is to say that people live with and grow as people with autism. Although Autism Speaks claims to fight against stigma, its representations of autism tend to be dark, frightening, and highly stigmatizing.

Because Autism Speaks frames autism as a disease, their homepage links to a variety stories from a bio-medical model, including a report regarding health, information on diagnosis and learning the signs of autism, and news of a genome project. Their research priorities are all medical: genome sequencing, global public health, the Autism treatment network, pre and postdoctoral fellowships that bridge clinical and laboratory science, and the Preclinical Autism Consortium for Therapeutics to support clinical trials. The largest portion of their funding is invested in bio-medical scientific research, much of it with the goal of eradicating autism. Their advocacy priorities list investment in research first, then legislation and services for adults to gain the support they need to live in the community as independently as possible.

In contrast, the depiction of disability as a disease that destroys children's and family's lives is almost never employed in modern campaigns by The Arc or UCP. That said, these organizations that focus more heavily on the social model also retain some aspects of the bio-medical model used to pursue cure and prevention. Although NDSS recently changed its mission statement to brand itself as «the leading human rights organization for all individuals with Down syndrome,» it has a long history of supporting medical research, clinical trials, and most recently initiatives like chromosome mapping and an NIH registry of individuals with Down syndrome. The Arc also has a long history of promoting medical research, including research on fetal alcohol syndrome, specific chromosomal disorders, human genome mapping, and gene therapy. Projects like genetic mapping and gene therapy are routes to prevention and eradication.

The tension between trying to value people with a disability and pursuing the eradication of that disability is challenging. The politics of cure/prevention positions the disability as inherently negative, something to be avoided, a thing that causes suffering.

Simultaneously, OLPs assert the value of people with that disability and include them as part of the human diversity to be respected and supported. Over time, as they prioritized the fight for civil rights and inclusion, The Arc and NDSS diminished their bio-medical focus. Autism Speaks, a more recent organization, places the biomedical model front and center. Although they recently removed the word «cure» from their mission statement in recognition of the sharp criticism they received from the disability activist community, Autism Speaks remains committed to an agenda that prefers a world without autism, thereby undercutting its ability to embrace neurodiverse people as valued and respected members of society.

Integration Versus Disability-Specific Sites And Services

Except for the Deaf community's support of deaf schools, integration is a fundamental goal of most OLPwDs. Activists with disabilities demand access to all aspects of mainstream society, supports and services in the community rather than in institutional settings, and freedom from discriminatory practices that create exclusion. OLPs, though, vary in the degree to which they fight for integration in all aspects of life. In line with OLPwDs, parents may demand access for their offspring to integrated schools, workplaces, leisure opportunities, etc., but parents also often value disability-specific settings and services due to the belief that these settings are best configured to provide expertise, safety and a sense of community among similar peers. In this category of integration versus disability-specific sites, we see three typical frames.

Integration

An integration agenda seeks the full and equal participation of people with disabilities in all of society's institutions, organizations, and valued social roles. The National Organization of Parents of Blind Children (NOPBC), for example, clearly asserts the value of integration. Their mission is the «complete integration of the blind into society on the basis of equality.» In their discussion, «where do blind children go to school?», they state, «Most children who now attend the residential schools for the blind have other disabilities in addition to blindness. Blind children in public schools are in regular classrooms and use a cane and read and write Braille. These blind students might work some of the time with a special teacher who would also help get the special books needed by blind children. These Braille books would contain the same things your books would have in print. Blind children take the same classes that the other kids the same age take.» (National Organization of Parents of Blind Children, «Questions Kids Ask,» n.d.). They criticize the use of sheltered workshops and instead advocate competitive employment opportunities. Blind skills and technologies are used, as well as accommodations and accessibility, to facilitate integration. Learning these skills, according to NOPBC, does not require nor justify long-term segregated education or segregation in other settings.

The Community Imperative, a philosophical and political statement demanding inclusion espoused by many disability organizations including The Arc and UCP, offers another example of the value placed on integration. The Arc's position statement on inclusion reads: «All people benefit when persons with intellectual and/or developmental disabilities are included in community life. People with disabilities should be welcomed and included in all aspects of our society. This includes public activities, programs and settings, and private establishments which are open and accessible to members of the general public. People with disabilities should receive the supports they need to participate actively in community life without having to wait» (The Arc, «Inclusion,» n.d.). The Arc

believes that the specific opportunities children with disabilities should have include: to live in a family home, to have access to needed supports, to enjoy typical childhood relationships and friendships, to learn in their neighborhood school in a general education classroom that contains age peers without disabilities, to participate in the same activities as children without disabilities, to play with other children in community recreation, and to participate in religious observations and practices. They believe that adults with disabilities should have relationships of their choosing with individuals in the community who are not paid staff or family, live in a home where and with whom they choose, have access to needed supports, engage in meaningful work in an inclusive setting, participate in recreation and leisure available to the general public, and participate in religious observances and practices of their choosing.

The pursuit of inclusion envisions a community composed of diverse people with diverse needs, in which the community values all members and provides the avenues needed to support all members in meaningful participation. Anything less is discrimination.

Least Restrictive Environment And Negotiated Access

Rather than full inclusion, Least Restrictive Environment (LRE) is a philosophy built into civil rights laws like the Individuals with Disabilities Education Act (IDEA) and into the service system for developmental and mental disabilities that states that people should have the maximal freedom possible given their capabilities and needs. This falls short of full inclusion, which is seen as an aspirational goal which may never be reached. In principle, LRE demands full inclusion unless there are clear reasons to restrict it, but sociologist Steven Taylor (1988) noted that in practice it has been used liberally to legitimize segregation when deemed by experts and parents to be in a disabled person's best interests (Evans, 2017).

A system based on LRE offers a «continuum» of services which vary in the levels of integration and freedom. For example, housing services might offer supports for independent living (full integration), small group homes with some staff supervision and restrictions in the community, group homes with significant supervision and restrictions with less community interaction, and facilities that are totalizing in nature such that, for example, agency rules dictate schedules and one has few contacts outside the disability service system. People with disabilities potentially move along the continuum based on professional assessments of their skills and successes at integration. According to OLPwDs, in practice this system too often presumes that restriction is acceptable, forces people to prove that they are worthy to be in the community, fails to teach people independent skills to advance them in the continuum, and determines placement based on open «slots» rather than a process that takes seriously why and when we should restrict liberty.

The Arc and UCP on the national level have moved increasingly towards advocating for full integration, but historically and still today retain strong elements of a continuum model in many of their local service delivery systems. On the one hand, both have supported the Community Imperative and pushed for integration in education, work, and community services. On the other hand, The Arc has a decentralized structure, and many local Arcs run disability-specific programs, including sheltered workshops, day programs, and agency-organized group homes. Placement in these settings often is determined by available «slots,» funding streams, and professionally assessed skills, rather than a presumption of full inclusion and meaningful consumer choice. For self-advocates, these systems are particularly problematic when there is an encompassing system of large-scale, disability-specific settings, so that «consumers» move from one disability-specific setting

to another, with little interaction with the community outside of the disability service sector and paid professionals, and with little control over these «services» and the content of them.

Shifting between the positions of full inclusion and LRE creates internal conflict within these organizations. The Arc's position on sheltered workshops and day programs offers a vivid example of internal conflict. Nationally, The Arc is moving away from sheltered workshops and towards support of competitive and integrated workplaces, and many state-level Arcs reflect national trends. For example, New York's Arc supported the move toward competitive employment, and several county-level Arcs began the process of transitioning their work programs to deliver integrated and competitive employment programs, such as the Rockland Arc which began converting its sheltered recycling workshop into an employer for both disabled and non-disabled workers. Not all local Arcs, though, were convinced of the value or possibility of full integration. Putnam County Arc Executive Director Susan Limongello (2014) cautioned, «This upcoming transition will force many people into jobs that they may not want. Their current situation [including employment at a sheltered workshop] affords them real work and successful employment» (quoted in Matthews, 2014). Hanns Meissner, executive director of the Rensselaer County Arc, stated, if not for sheltered workshops and day programs, «They might otherwise be in nursing homes» (quoted in Karlin, 2013). In other words, ending sheltered workshops might lead to negative, rather than positive, consequences if people cannot find or successfully fulfill the demands of competitive employment, and they may instead end up in even more restrictive and unfulfilling programs. Given a lack of confidence in both the ability of all people to hold competitive community-based employment and the willingness of employers to include and accommodate diverse employees, many parents fiercely defend sheltered workshops as an appropriate and valuable service to foster economic productivity and social participation.

In his study of The Arc, Larry Jones (2010) notes that local Arc chapters tend to be more conservative and parochial, more focused on service delivery, and are typically dominated by parents seeking benefits for their children as compared to the national and state-level organizations — levels which have more «cosmopolitan» leaders focused on advocacy and rights.

Disability Specific Services And Settings

Some OLPs operate within the LRE theoretical framework but focus their efforts on ensuring the provision of disability-specific settings. This approach is treated as a distinct frame, and there is a great deal of variability within this frame. In particular, some organizations advocate access to short-term disability-specific services in a disability-specific setting, while others advocate long-term disability-specific services and sites that tend to encompass the entirety of a person's lived experience (e.g., education, work, leisure, housing) over the life course. The former is far less controversial than the latter.

As noted earlier, the Deaf community stands apart from most grass-roots disability activist organizations. The Deaf community sees itself as a linguistic and cultural minority and, as such, demands the means to transmit its culture and language via Deaf education provided by Deaf educators in Deaf schools (Lane, 2006). In an information booklet for parents, the American Society for Deaf Children notes that «a center-based program brings a group of students with similar needs together in a centrally located school,» with full access to ASL, accommodations, and involvement of Deaf adults. Hands and Voices, an organization of parents of Deaf and hard-of-hearing children, has no advocacy or policy branch, but it does offer resources including the National Association of the Deaf (NAD)

statement on early access to ASL and inclusion: «Placement of all deaf and hard-of-hearing children in regular educational classrooms in accordance with an inclusion doctrine rooted in ideology is a blatant violation of the IDEA» (National Association of the Deaf, 2002). NAD has taken a strong stand against educational integration and instead promotes the use of Deaf schools, including residential placement. The value of Deaf education in a Deaf-specific setting is tied to fostering Deaf skills and culture, rooted in early association with the Deaf community and led by Deaf adults, leading to empowered adult integration across social arenas (e.g., employment, healthcare) facilitated by access to ASL interpreters. As this is a stance taken by the Deaf activist community to empower Deaf children and adults, it is seen as an acceptable choice by most OLPwDs although it challenges the integration mandate.

OLPwDs have a much more antagonistic view toward OLPs, such as VOR (formerly Voice of the Retarded), that fight to retain long-term, large-scale, disability-specific settings, including state-run residential facilities and sheltered workshops. Fighting against long-term, disability-specific settings is a core value of OLPwDs.

VOR and other organizations that use this frame see value in concentrating professional expertise, centralizing services, offering a high level of supervision, and creating an environment that they perceive to be safe. They argue, in light of LRE guidelines in federal law, that disability-specific settings are a required option and that disability-specific settings might be the most appropriate and least restrictive setting in which to serve particular people with disabilities. The VOR homepage, for example, explains to visitors «Your Legal Right to an Intermediate Care Facility»: «Despite a deinstitutionalization effort by those opposed to congregate care, the ICF/IID program remains a legally enforceable federal entitlement under Medicaid» (Voice of the Retarded, n.d.). In other words, they criticize deinstitutionalization and present large, disability-specific residential settings as within one's rights, not a violation of them—the polar opposite of the message of activists with disabilities. This news is immediately followed by the heading, «Widespread abuse, neglect, and death in small settings serving people with intellectual disabilities.» The accompanying story documents the range of «tragedies» that occur due to the «zest to move to a community for all» vision for people with developmental disabilities without adequately considering the ramifications of separating vulnerable people from specialized care and then doing away with a critical safety net (a/k/a deinstitutionalization). VOR activists share with OLPwDs concerns over lack of safety in the community; however VOR uses this concern to justify congregate care (with little attention to the abuses in congregate care) whereas activists with disabilities use this concern to demand more funding, training, and choice within the community.

VOR parents draw parallels between specialized education and care for people with intellectual disabilities and Deaf education (as well as retirement communities and other places where people with similar needs share services). The comparison falls flat for OLPwDs, however. In contrast with Deaf education, few disability-specific skills are taught in congregate care for people with intellectual and developmental disabilities (ID/DD). For people with ID/DD, the key educational issues are the pedagogical techniques, pace, and level of education, not the attainment of different skills such as ASL. Unlike Deaf schools, which employ significant numbers of deaf adults as teachers and administrators, agencies in the field of ID/DD rarely hire people with ID/DD in positions of power. Nor is there a focus on the dissemination of a disability culture. Instead, the goal is typically perceived as maximal normalization (attaining the greatest skills to fit within the typical culture) and/or separation. For OLPwDs, integration, not segregation, is the most effective path to

participation and acceptance. And, unlike Deaf education, disability-specific services for people with ID/DD might encompass residential, work, and recreation, throughout the lifespan, creating a totalizing experience separate from people without disabilities (except for employees and volunteers) run by non-disabled professionals. Thus, support for a totalizing system of disability-specific sites for education, employment, leisure, residence, and other services for people with ID/DD is far more removed from the core of OLPwDs than support of Deaf education.

For organizations focusing on mental illness, the fight over integration is also very heated. Many people with mental illness can and do benefit from treatment provided in the community. Since deinstitutionalization, it has become difficult to institutionalize someone for mental illness. In most states, evidence of harm to oneself and others are the only legal bases for involuntary commitment. Under this standard, people with mental illness might be homeless, unsafe, unable to take care of their basic needs, and/or in distress and without appropriate treatment, yet still be ineligible for involuntary commitment. Some parents and family members have fought to loosen the legal requirements for involuntary commitment and to create a procedure for mandated outpatient treatment for some people living in community settings. NAMI executive director, Laurie Flynn, states, «many families with a schizophrenic son or daughter have been extremely distressed because the commitment laws mean they have to wait for a crisis before they can get help, and they have to become legal adversaries» of their children in the process if their offspring refuse help (quoted in Goleman, 1986).

NAMI's official position states, «States should adopt broader, more flexible standards that would provide for involuntary commitment and/or court ordered treatment when an individual, due to mental illness is gravely disabled, which means that the person is substantially unable, to provide for any of his or her basic needs, such as food, clothing, shelter, health or safety; or is likely to substantially deteriorate if not provided with timely treatment; or lacks capacity, which means that, as a result of the serious mental illness, the person is unable to fully understand–or lacks judgment to make an informed decision about–his or her need for treatment, care, or supervision» (National Alliance on Mental Illness, «Right to Treatment,» n.d.).

In the case of involuntary commitment and treatment, the issue of integration versus disability-specific services is not at all related to an empowered choice to participate in a disability community or disability culture. Rather it imposes a disability-specific setting, and asserts medical authority and treatment on a person who resists such treatment and restricts their right to resist. Many NAMI advocates see this treatment as essential for protecting the safety and well-being of people with mental illness, imposing care until the person can better engage in self-care. Indeed, for many parents and siblings, the right to integration is a ridiculous notion if their loved one is homeless, off their medications, and/or in danger. Integration under those circumstances hardly seems empowered. However, support for involuntary commitment and treatment using any measure other than harm is far removed from the core of OLPwDs.

Power And Voice

A third major controversy related to framing and disability activism is the issue of power. Who speaks for people with disabilities and who makes what decisions in what settings? The position of OLPwDs is that these decisions should be made to the greatest extent possible by people with disabilities, but many OLPs place power in the hands of parents and professionals. This distances OLPs from core OLPwDs. We identify three

typical configurations of the relationship of power and voice revealed in the tenets of OLPs.

Conferring Leadership To Activists With Disabilities

Although relatively rare in the scope of parent activism, some parents are members of OLPwDs. Among the organizations discussed in this article, the National Organization of Parents of Blind Children (NOPBC) best illustrates this model. NOPBC is a sub-unit of the National Federation of the Blind. As such, parents are organized within and under a governing body controlled by people who are blind. The mission, funding, and policy decisions are all tied to the larger body. Parents are therefore positioned as allies to blind activists, rather than as competitors for authority, funding, and political power.

Using a different organizational model, the American Society for Deaf Children states that their board is «a group of dedicated parents and professionals» with no explicit reference to quotas of parents and/or deaf individuals in governance. That said, of the ten board members listed on their website with biographies (one board member had no biography), all (100%) were Deaf or hard of hearing, three identified as Deaf parents of Deaf children, and seven listed some affiliation with Gallaudet University. Thus, although positioned rhetorically as a group of parents and professionals, the board is a very specific set of parents and professionals who are themselves Deaf and wish to educate and shape the experiences of children who are Deaf.

Parents have also joined and/or offered support to self-advocacy organization, both because they as parents might have disabilities and/or to support the self-advocacy of their offspring. Blogger and parent of a nonspeaking autistic youth of color, Kerima Cevik regularly critiques parent-led autism organizations and aligns with autistic activists and organizations to promote grassroots community-building and pay-it-forward activist models (Cevik, n.d.). Many self-advocates with intellectual and developmental disabilities speak about the positive role their parents have played in supporting their self-advocacy, including providing transportation, assisting in preparing and delivering speeches, and co-presenting. Zona Roberts, mother of disability rights leader Ed Roberts, offers another useful example of a mother who fought for her son's inclusion, and then as he matured, supported his activism (Brown, 2000). In this model, parent advocacy may be largely behind the scenes, supporting their family members in taking the lead.

Parental Control With Inclusion Of Self-Advocates And Professionals

The most common strategy of OLPs is to build avenues of inclusion for family members, self-advocates, and professionals, while retaining considerable control themselves as parents. For example, NAMI's bylaws require that at least 75% of their board of directors be a person with or who had a mental illness, or parents or relatives of a person with mental illness. They established a Peer Leadership Council of people who have/have had mental illness, and the chair of that council automatically sits on the board. Using the biographies listed on the NAMI website, of the five member board leadership team, one person identified as a parent, two as family members, and one as a person with a mental illness diagnosis. Looking at the sixteen-person board (including officers), six identified as parents (38%), three as siblings (19%) (therefore, 56% identify as parents/family), and five as people with a mental illness diagnosis (31%). 4 Parents outweigh self-advocate control, but NAMI's board also has a sizable percentage of people with mental illness in leadership positions as well as a council to advance the interests of self-advocates. Among staff leadership positions (e.g., executive director, director of marketing) listed on the website, only one of thirteen (8%) staff members identified as a family member and no (0%) staff identified as people who have/had mental illness.

NAMI's programming priorities reflect a value on self-advocacy, including supporting the Peer Leadership Council, stressing person-centered participation in treatment and research, and providing tools for advocacy and involvement. That said, NAMI does little to draw attention to or ally with the psychiatric survivors' movement or Mad activism which is critical of psychiatric intervention.

The Arc bylaws require that a majority of the board of directors be parents or family members of people with ID/DD or people with ID/DD. They also established a national self-advocates council and a siblings' council, among other councils, to serve in an advisory capacity. Of their board in Fall 2017, four of the five (80%) national officers were parents. Of the entire board (including officers), sixteen of 24 board members (67%) listed could be clearly identified as parents, family members, or self-advocates. This included nine parents, four family members, and three self-advocates. 5 Here we see a dominance of parents and family members (54%), as compared to people with disabilities (13%). The Arc listed 47 staff members, 42 of whom have bios listed on their webpage. Of these, three identified as parents, six as family members (21% parent/family), and one as a person with a disability although not clearly with an ID/DD diagnosis (2%). No self-advocates or people with ID/DD were identified among the staff (0%). Thus, in the day-to-day work of the organization, family members still have some representation, while self-advocates and people with ID/DD diagnoses have little to none. The national bylaws require local chapters to meaningfully involve parents, family members, and people with ID/DD in leading and guiding the chapter, but offer no specific percentage of the board nor other specific guidelines for meeting this requirement. Thus, local chapters have more leeway in their board composition and likely have less involvement by self-advocates.

Looking at their programming, Arc support of self-advocacy is substantial, including the self-advocacy council and an online forum for self-advocates. Many state and local chapters support self-advocacy efforts by providing funding, space and supports, and fostering recruitment. They also work closely with Self-Advocates Becoming Empowered—the national self-advocacy group for people with ID/DD—and state-level self-advocacy groups. On the other hand, The Arc boasts being «the nation's leading advocacy organization for all people with ID/DD and their families,» clearly asserting their power and prestige above that of Self-Advocates Becoming Empowered.

Parental And Professional Control

Some OLPs focus almost exclusively on parent/family leadership. VOR, for example, has a sixteen-member board, of whom fifteen (94%) are parents and/or siblings. One member is a caregiver, and none are self-advocates. There are no bylaws mandating any particular representation, although historically the board has always focused on family membership. They have almost no history of alliance with self-advocacy organizations, and they present themselves as the voice of people with ID/DD (or at least those who lack the skills to speak for themselves).

Autism Speaks lists a board of 29 members, including twelve parents, two family members, and one self-advocate (an email with staff reported two self-advocates on the board), thus the board composition was 48% parent/family and 7% self-advocate (if we use the number reported in the email, 3% if we use website disclosure). Autism Speaks has no bylaw regarding representation of parents, family members or self-advocates, and participation by self-advocates is a recent change likely resulting from criticism by autistic activists and OLPwDs. Its website lists six staff leadership positions, and of these one (17%) is filled by a self-identified parent, and none (0%) by people who self-identify as autistic. Autism Speaks offers few resources for self-advocacy and no clear projects to

foster or advance self-advocacy. As will be seen, Autism Speaks also rarely seeks to ally with autistic self-advocates or OLPwDs, and instead prefers to connect with medical, psychiatric, and behavioral health professionals and the pharmaceutical industry to support their agenda of medical research and treatment.

Although historically an OLP, UCP's current decision-making structure is dominated by professionals. UCP's website lists five officers and thirteen trustees. Of this eighteen-person board, five are parents or siblings (28%) and two are people with cerebral palsy (11%). In total then 39% of the board is composed of parents, family and/or people with disabilities. The rest are people who offer professional expertise. UCP has no bylaws regarding representation of their board, and thus no requirement for self-advocate representation. Unlike VOR and Autism Speaks, though, UCP has a strong record of supporting self-advocacy and working with OLPwDs. As such, it breaks the expected pattern that organizations with more emphasis on the social model and integration would also ensure leadership for people with disabilities.

Positionality And Alliance

As one can see, there is no simple, definitive typology of OLPs. UCP emphasizes the social model and inclusion, yet has no rule for self-advocate board representation and limited participation. American Society for Deaf Children has a high representation of Deaf people on its board and relies heavily on the social model, but supports Deaf education delivered at schools specifically for the Deaf rather than at integrated schools.

That said, we see a tendency for support of the social model, integration, and power of self-advocates to cluster and in effect to position organizations closer to OLPwDs and orient them towards alliance with these organizations, although the complex blending of frames and the retention of parental/professional control by OLPs makes even these organizations «sometimes allies.» On the other hand, reliance on the medical model, disability-specific settings, and parent/professional control tend to cluster and in effect to position OLPs further away from, and even in opposition to, OLPwDs and orient them more toward peripheral organizations like medical and human service industries. These organizations are less likely to form alliances. However, even when organizations do not agree in philosophy and oppose each other in some ways, they do at times engage in strategic alliances to support particular issues.

Because the National Organization of Parents of Blind Children exists as a subdivision of the National Federation of the Blind, the policy priorities are in sync. They «function as an integral part of the National Federation of the Blind in its ongoing effort to achieve equality and opportunity for all blind persons.» Alliance is a direct outcome of the organizational structure.

In contrast, The Arc and UCP are independent organizations which are relatively consistent allies of grass-roots disability organizations, but also pursue priorities less reflective of the disability rights or justice agenda and more geared toward achieving support for families and service providers. For example, the Disability Integration Act of 2017 (H.R. 2472) works to ensure the provision of long-term services and supports in the community, and this goal is a central priority of many OLPwDs. Alongside The Arc and UCP, supporters of this bill include disability activist organizations such as ADAPT, American Association of People with Disabilities, Autism Self-Advocacy Network, Little People of America, Disability Rights Education and Defense Funds, National Council on Independent Living, National Disability Rights Network, Not Dead Yet, and Self-Advocates Becoming Empowered. OLPs notably missing, for example, are Autism Speaks and VOR who lack a focus on integration and strong ties with the disability community.

Reflecting a broader blend of alliances, the Steve Gleason Act of 2017 (S. 1132), which protects access to speech-generating devices through Medicare, is supported by The Arc and UCP, a range of OLPwDs (e.g., Autistic Self-Advocacy Network, Disability Rights Oregon, National Disability Rights Network, Not Dead Yet), and professional/health organizations (Aging Life Care Association, Medicare Rights Center, Association of Assistive Technology). Again, we see Autism Speaks and VOR are notably absent.

Other priorities of The Arc and UCP, such as the Raise Family Caregiver Act (H.R. 3759, S 1028), attract mostly professional alliances rather than OLPwDs. This bill directs the Department of Health and Human Services to create a National Family Caregiving Strategy and Council in order to support family caregivers. The Paralyzed Veterans of America is listed among the supporters, but other OLPwDs are not. Instead, the list is composed primarily of health, aging and professional organizations, such as Alzheimer's Association, American Academy of Family Physicians, Christopher and Dana Reeve Foundation, Family Caregiver Alliance, and National Council on Aging. Autism Speaks and Autism Society are both collaborators, but the Autism Self-Advocacy Network is not. The Arc and UCP are supporters, but Self-Advocates Becoming Empowered is not. Grassroots OLPwDs are not clearly opposed to Raise Family Caregiver Act; rather, it is not their priority.

The Arc and UCP frequently collaborate with a set of professional organizations dedicated to issues related to intellectual and developmental disabilities. These organizations include the American Association on Intellectual and Developmental Disabilities, American Network of Community Options and Resources, and the National Association of Councils on Developmental Disabilities. In collaboration, they created the Public Policy Agenda for the 115 Congress 2017-2018. SABE, representing self-advocates with intellectual and developmental disabilities, was not listed as part of this working group, nor was VOR, representing parents who seek congregate, specialized care. Thus, we can see for The Arc and UCP a tendency toward alliance with OLPwDs mixed with priorities that instead draw collaboration with professional and other parent groups.

When we look at NAMI's alliances, we see greater distance from the community of OLPwDs. Certainly there are shared policy issues, but NAMI's priorities are often not the priorities of OLPwDs and vice versa. In the fall of 2017, the primary legislative priorities that NAMI promoted were two bills to promote mental health care reform: Helping Families in Mental Health Crisis Act of 2016 (HR2646) and Mental Health Reform Act of 2016 (S2680). Both pieces of legislation sought to increase access to mental health treatment in part through broadening the use of involuntary institutionalization and mandated treatment. To use HR2646 as an example, it expands Medicaid reimbursement for in-patient care, gives families greater access to medical information, and allows and expands mandated treatment in the community. In her letter of support to Representatives Johnson and Murphy, co-sponsors of the bill, NAMI executive director Mary Giliberti stated:

NAMI is pleased that HR 2646 includes a range of reforms that would improve our nation's failing public mental health system including efforts to focus on outcomes, break down barriers for consumers and families to access treatment, and expand the availability of evidence-based practices.

We are particularly appreciative of provisions in your legislation that will expand efforts to ensure full implementation and enforcement of the Mental Health Parity and Addiction Equity Act (MHPAEA). Your legislation would also improve integration and program coordination across multiple federal agencies that serve people living with

serious mental illness and remove discriminatory impediments to mental healthcare. HR 2646 also contains provisions designed to improve the integration of mental health and physical health care in Medicaid, spur early intervention in the treatment of psychosis, improve the use of health information technology in mental health care, and provide resources for suicide prevention (Gilberti, 2005).

In the support of these legislative efforts, NAMI was joined by the Mental Illness Policy Organization and Mental Health America, leading professional associations related to mental illness.

However, OLPwDs, including the National Coalition for Mental Health Recovery (NCMHR) and the National Disability Leadership Alliance (NDLA), opposed both these bills. NCMHR's mission is to ensure that mental health consumers and survivors have a major voice in the development and implementation of mental health care policy. These groups object to the rights restrictions built into the law, as well as the control given to family members who may be part of the mental health problem. Describing the bill, NDLA stated it would «silence our voices, reduce our choices, compromise our rights and restrict programs that protect our rights and safety. It would increase the use of involuntary outpatient commitment, coerced psychiatric treatment and hospitalization, heralding a return to the failed policies of the past» (National Disability Leadership Alliance, 2015). The framing of the law is also deeply problematic from disability rights and justice perspectives. In the database tracking all Congressional bills, the summary of the bill reads: «Most Republicans argue that the main issue causing mass shootings is not guns but mental illness. HR2646, the Helping Families in Mental Health Crisis Act, is the main bill in this Congress tackling the issue of mental health» (GovTrack, 2016). This framing encourages stigma against people with mental illness and promotes the notion that social control is necessary, albeit through mental health rather than imprisonment. Although NAMI and the disability activist community share a concern with the lack of appropriate mental health care and support, the social control perspective embedded in this law is deeply antithetical to OLPwDs.

Autism Speaks' advocacy agenda has clear points of contention in relation to OLPwDs, and they are positioned even further away from the disability rights and justice core. In listing their «legislative wins» in 2016, the top achievement is an increase in National Institute of Health funding to «accelerate biomedical innovations for people with autism.» This act was broadly supported by a range of health organizations such as the National Health Council, American Aging Association, ALS Association, American Foundation of the Blind, Association of University Centers on Disability, Easter Seals, Mental Health America, National Alliance for Caregiving, National Down Syndrome Association, and the Spina Bifida Association. However, most of the organizations in the National Disability Leadership Alliance did not sign on as their focus is inclusion and rights, not cure and biomedical solutions. Autism Speaks also builds alliances with the bio-medical community by funding and encouraging bio-medical research; for example the website applauds the creation of an «an international consortium of scientists, led by Roche, King's College London, and Autism Speaks» who will be «collaborating on one of the largest ever academic-industry research projects to find new methods for the development of drugs for autism spectrum disorder (ASD)» (Autism Speaks, 2012). Autism Speaks lauded successes in extending insurance coverage for applied behavioral analysis (ABA). Contrary to this position, though, the Autism Self Advocacy Network, states: «Until now, much advocacy for coverage of 'autism interventions' has focused on purely behavioral approaches, like Applied Behavioral Analysis (ABA). These interventions can be

inappropriate or even harmful, and exclusive focus on coverage for behavioral interventions can result in limited access to evidence-based and emerging models that focus on improving relationships, communication skills, and development of skills that are meaningful to individuals' quality of life» (Autistic Self Advocacy Network, n.d.). Autism Speaks' marketing decisions, which often present autism in a very negative light, also frequently put it at odds with the disability activist community. Autism Speaks' board showcases its strong relationships with the corporate world and a corporate perspective, with many board members in positions from marketing, investment, and the media at major corporations, and few members who represent social justice expertise. It has also been criticized for accepting donations from the pharmaceutical industry. 6

Autism Speaks, though, does share a few priorities with OLPwDs and with other OLPs focused on developmental disabilities. For example, the ABLE Act (Achieving a Better Life Experience Act of 2011) created the opportunity for tax-free savings accounts to be used for disability-related expenses. Interestingly, although the disability community was initially unified behind the ABLE Act, late in the course of its development politicians inserted a modification which allowed accounts only to people with disabilities manifest before the age of 26. A broad coalition under the banner of the Consortium for Citizens with Disabilities signed a letter that opposed expansion of ABLE benefits for eligible individuals without addressing the age restriction that left many people with disabilities without access. The coalition included organizations such as The Arc, UCP, National Council on Independent Living, National Disability Rights Network, United Spinal Association, and Paralyzed Veterans of America. Neither Autism Speaks nor National Down Syndrome Society, two of the lead organizations in advocating the ABLE Act, signed the letter, forgoing their cross-disability alliance to ensure broader access to benefits to their own constituencies.

Among the organizations studied, VOR is most consistently in a position of antagonism to OLPwDs. While NAMI and Autism Speaks deal with a broad array of issues relating to their constituency and at times find points of collaboration with OLPwDs, VOR focuses on ensuring a «full range of quality residential options and services» (Voice of the Retarded, «About») including large-scale, specialized facilities, which OLPwDs view as institutions and vehemently oppose. Thus, they are not simply pursuing different priorities or at times at odds; they are almost always in direct opposition. VOR's home page, for example, announces its opposition to a lawsuit filed by Disability Rights Ohio (DRO). The lawsuit, Ball v. Kasich, alleges that, in violation of the ADA and other laws, Ohio has not sufficiently prevented unnecessary institutionalization, and the DRO demands Ohio do more to provide services in the community. VOR opposed this lawsuit, filed an amicus brief in opposition, and raised funds to support «the rights of families in opposing this action.» VOR's focus on maintaining specialized facilities offers almost no opportunities for alliance with OLPwDs. In fact, the antagonism is so sharp that VOR is routinely ignored, excluded from participating even in shared interests like community safety standards, and mocked. The Ragged Edge, a magazine of the disability activist community, described VOR in their «The Gag» section as «a group of parents who once dumped their kids in institutions and today grease political wheels to keep them there.» They created a cut-out «puppet» of VOR founder Polly Spare saying things like «Frankly, my dear, they drooled. And in public! They were just... damp! All day long!» (Ragged Edge, 1998). VOR allies primarily with unions and provider agencies that have a stake in the survival of specialized facilities rather than OLPwDs,

In summary, we can imagine a field of disability activism situated around a core of OLPwDs as represented by grass-roots self-advocacy organizations working toward equality and empowerment. Outside of the core, but often in alliance, are OLPs like The Arc and UCP, which support self-determination and often advocate for rights and equity, but also serve the interests of parents, act as service providers reliant on bureaucratic models of management and disability-specific settings, and preserve political power for parents rather than people with disabilities. Further away from the core are organizations with a heavier focus on treatment such as NAMI, although they still have points of collaboration such as fighting stigma and increasing self-advocacy. Autism Speaks is well distanced from the core of OLPwDs due to its highly medicalized view of autism, its support of treatment in professionally controlled spaces, and its relative lack of attention to issues of social rights, equity, and justice. VOR is outside of the field, considering itself a disability rights organization, but viewed by grass-roots OLPwDs as completely antithetical to their mission.

Second, the very fact that OLPs are parent-led tends to place them outside of the core of disability rights and justice activism, subverting the ideal of empowerment and self-determination for people with disabilities. That said though, some organizations (at some times, for some issues) are much more involved and integrated into disability activism, and this is achieved by recognizing the value of the social model, embracing integration and equality, striving to support and empower self-advocates, and building consistent alliances with OLPwDs. On the other hand, other organizations (at some times, and for some issues) are positioned much further away from the core of OLPwDs, and indeed at times in opposition to it, especially insofar as they embrace a medical model, advocate for policies counter to integration and equality, deny self-advocates a voice, and build alliances with professionals and corporate interests rather than with disabled activists.

Third, organizational complexities mean that internal frames and external alliances might shift frequently, yielding potential, yet suspicious and unreliable, alliance with OLPwDs. As seen, The Arc both supports The Community Mandate and runs sheltered workshop and day programs at disability-specific sites. NAMI prioritizes the fight against stigma and discrimination, but also values the medical model (although with a focus on patient self-determination and involvement) of treatment and recovery. UCP draws on the social model of disability, yet has no guideline for board representation by self-advocates and includes few on their board. Each organization struggles with the ways in which it embraces disability activism and allies with OLPwDs while catering to its base of support, parents who ultimately want to retain control over treatment service options for their children – a desire that is deeply problematic from the perspective of OLPwDs.

New social movements seek to upend traditional identity politics and gain cultural affirmation of the value of particular people. Thus, in new social movements, it is imperative the marginalized people are seen as owning and leading their own movement. The political process itself is key to achieving the end. The very power of OLPs thereby potentially undermines OLPwDs, especially when they present different frames and priorities than do OLPwDs. The Arc, for example, reported net assets in 2016 of more than 16 million dollars, far larger than most OLPwDs, thereby giving The Arc a political weight that is difficult for OLPwDs to match. Parents, however, rarely recognize this tension or their privileged position. Indeed, parents rarely feel powerful. In the face of massive bureaucracies, fiscal policies, laws, and professionals, parents struggle to have their voices heard, and opposition by people with disabilities may seem like one more threat, further undercutting their vulnerable position. Activists with disabilities, with their ideals of

integration and empowerment, may feel like yet another outsider placing pressure on an already tapped family, and yet another group that wants to invalidate their voice. Thus, while OLPs and OLPwDs often work in concert, alliance can be tense to say the least.

Ultimately, strong partnerships can be built when OLPwDs reach out to include parents and offer them avenues to gain knowledge of and access to disability activism. The model of the National Federation of the Blind may serve as useful in this regard, as it actively incorporates parents into their organizational structure. Parents too must come to appreciate the long-term value of the empowerment of people with disabilities in society. Parents may want to prioritize the individual needs of their child and harness their resources to attain their goals most efficiently. But eventually their child will grow into an adult, and building a society that respects the self-determination of adults with disabilities will yield positive results in the long-term.

Thus, we must build pathways towards interdependence, in which parents are supported by leaders in the disability community in enacting valued roles and disabled activists are supported by parents in the achievement of rights and justice. Moreover, as we strengthen the pathways for alliance, we must be mindful that disability activism led by disabled activists and by parents had been dominated by white activists with class privilege, especially on the national level (Erkulwater, 2018; Frederick & Shifrer, 2018; OToole, 2015), and that alliance building must consider ways to include the diversity of families and people with disabilities. While we aim for alliance, we should also recognize that alliance is rarely without costs and sacrifices, and we must recognize these as well; parents, and specifically parents with class and race privilege, have their own interests and may not forgo their voice to strengthen the political position of activists with disabilities. Alliance may strengthen one's position with shared causes, but parents do not always share the perspective and interests of activists with disabilities and thus they will continue to exert an independent and politically influential voice, and to negotiate with OLPwDs regarding the goals of disability policy and programs.

Future Research

This research highlights variation among OLPs, but there is much research left to do. This research focuses on several large, national OLPs, and future research should look at a broader array of types and levels (national, state, local) of organizations. We chose to look at the public positioning of formal, national organizations due to their political power, but the correlation between the official positions of an organization and the beliefs of its members may not be strong. Thus, member studies would yield additional interesting information about the effect of various organizational frames and the points of alliance. Examining local level activism and its relationship to national activism would also yield greater information about the frames and strategies used by activists (parents and those with disability) of color and in marginalized communities and the dynamics across various communities in building alliances and developing policy directions.

We also focus on discourse and legislative alliance, but organizations use a variety of social change strategies, and examining the varied strategies in the disability field would yield additional information about alliance. For example, ADAPT relies heavily on civil disobedience, but OLPs rarely use this strategy; thus, ADAPT and OLPs may ally on the legislative efforts but not on the grass-roots tactics – tactics which require tremendous self-sacrifice - to promote the legislation.

Parents yield considerable power in disability politics, a power that has both propelled the emancipation of people with disabilities and undermined it. Pursuing a greater understanding of parental politics and the points of alliance and opposition with

OLPwDs therefore yields both practical and theoretical contributions for the areas of disability activism and policy.

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